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ABSTRACT

Aims: The overarching goal of this project was to establish a group comprised of a variety of TBI stakeholders for the purpose of: (1) determining facilitators and barriers in management of neuropsychiatric symptoms after TBI; (2) identifying strategies for maintaining a TBI PCOR network; (3) enumerating research topics related to TBI neuropsychiatry; and (4) highlighting policy changes related to TBI neuropsychiatry.
Methods: Twenty-nine TBI stakeholders participated in focus group discussions. Qualitative analyses were conducted both manually and using Dedoose software.
Results: Participant-identified barriers included stigma associated with experiencing neuropsychiatric symptoms and poor insurance coverage. Facilitators included treatment focused on education of neuropsychiatric symptoms after TBI and having a comprehensive caregiver plan. Best strategies for maintaining TBI PCOR network included having a well-defined project, continued regular meetings, and on-going education of network members. Pertinent research topics included TBI and aging, factors influencing outcomes after TBI, substance use disorders related to TBI, and effectiveness of telemental health services. Needed policy changes included making TBI neuropsychiatry education accessible to stakeholders and improving accessibility of TBI neuropsychiatric care.
Conclusion: TBI stakeholders identified several facilitators of care for neuropsychiatric symptoms after TBI and suggested research topics and best practices for conducting PCOR in this area.

Introduction

The development of neuropsychiatric symptoms after a traumatic brain injury (TBI) is common and is associated with a host of negative outcomes. The entire spectrum of TBI severity, ranging from mild to severe, is associated with increased neuropsychiatric morbidity (1,2). Approximately 40% of individuals who sustain a TBI experience two or more psychiatric disorders (2,3) and a similar percentage experience at least one unmet need for cognitive, emotional, or job services one-year post-injury (4). In a study on population estimates of health and social outcomes, Corrigan et al. (5) noted that at five years post-injury more than 50% of the persons with TBI were not able to perform many of their pre-injury activities and almost 40% had declined from premorbid levels of ability. An informal survey conducted jointly by the Brain Injury Association of Maryland (BIAMD) and Johns Hopkins University revealed that attendees of the 2016 BIAMD annual meeting identified lack of awareness about resources for neuropsychiatric symptoms following TBI and inadequate research on diagnosis and management of such symptoms after TBI as major barriers to treatment and recovery. A published study of facilitators and barriers to care for such symptoms among persons with TBI revealed that insurance issues, transportation issues, and financial issues were barriers to individuals receiving appropriate neuropsychiatric care (6).

The extant evidence therefore suggests that many individuals with neuropsychiatric symptoms after TBI suffer silently because they are unaware of the nature and functional impact of these symptoms and/or have difficulty accessing mental health care. Developing optimal methods for assessment and management of neuropsychiatric symptoms following TBI will require studies guided by integrated clinical, neurobiological, and patient-centered research approaches (7). A necessary first step toward optimal assessment and management of neuropsychiatric symptoms among persons with TBI is collaboration between persons with TBI, caregivers, clinicians, researchers, policymakers, and other TBI stakeholders on the creation of a TBI PCOR network, i.e. a network focused on patient-centered neuropsychiatric care and research on TBI that is able to ask and answer questions that are important to patients and that contribute to their care.

To address this need, this PCORI-funded engagement project had two overarching aims (1): to build and grow partnerships with relevant TBI stakeholders including persons with TBI, caregivers of persons with TBI, and healthcare academics, professionals, and policymakers; and (2) to develop

a formal program of TBI patient-centered outcomes research (PCOR) focused on identifying research topics and health-care policies related to TBI neuropsychiatry. The specific aims of the project were to facilitate TBI stakeholder group discussions about (1): facilitators and barriers to management of neuropsychiatric symptoms after TBI (2); the best strategies for continued engagement and maintenance of a TBI PCOR network of stakeholders (3); pertinent TBI neuropsychiatry research questions/topics; and (4) needed policy changes related to neuropsychiatric symptoms after TBI.

Methods

This project was reviewed and approved by the Office of Human Subjects Research Institutional Review Board (IRB) at Johns Hopkins Medicine. Procedures for obtaining informed consent and evaluating the capacity to give informed consent followed the protocol approved by that IRB. The project was performed in two phases. The first phase focused on establishing a TBI PCOR network of stakeholders. The second phase engaged the members of that network in group discussions focused on the four specific aims of the project.

Phase 1: establishment of TBI PCOR network

A diverse group of TBI stakeholders composed of persons with TBI, caregivers of persons with TBI, healthcare providers (e.g. physicians, occupational therapists, physical therapists, speech-language pathologists, mental health therapists, program coordinators, mental health clinic administrators) with experience-serving persons with TBI, and educators with expertise in TBI was convened. Stakeholders were 18 years of age or older, English speaking, able to participate in an on-site focus group lasting two hours, and able to attend four research education classes. Participants with TBI (of any severity) had to have been diagnosed by a qualified healthcare professional at least three months and no more than five years prior to participating in this project and as having neuropsychiatric symptoms after TBI. Caregivers of persons with TBI must have performed this role for at least three months prior to participating. Care coordinators and clinic administrators were required to have coordinated the care of at least 10 people with TBI and clinicians (physician, non-physician) must have treated at least 10 people with TBI.

Exclusion criteria for this project included: age less than 18 years; inability to provide written informed consent; non-traumatic brain injury (e.g. vascular brain injury, hypoxic-ischemic brain injury, toxic brain injury); serving as a caregiver for persons with only non-traumatic brain injuries; medical and/or psychiatric conditions of sufficient severity to preclude engagement in the project; and active suicidal and/or homicidal ideation or physically violent behavior in the year preceding project participation.

The leadership team for this project included a subspecialist in Behavioral Neurology & Neuropsychiatry with clinical and research experience on TBI (VR) as well as three co-leaders from different professional backgrounds – a behavioral psychologist (LB), the Executive Director of

BIAMD (PTB), caregiver of a person with TBI and a project coordinator. There were five advisory board members with complementary backgrounds: a person with TBI, a caregiver, a neuropsychologist (KTB), a mental health therapist, and a TBI educator. The two consultants included a subspecialist in Behavioral Neurology & Neuropsychiatry with extensive clinical and research experience in TBI (DBA) and a neuropsychologist with extensive clinical and research experience in TBI from a Veteran Affairs Medical Center (AJ). The two partnering organizations included the BIAMD and Brain Injury Association of America (BIAA).

Participants were recruited using flyers/advertisements. In addition to posting the flyers on the websites of BIAMD and distributing them electronically in BIAMD's weekly newsletter, flyers were distributed to various brain injury clinics in the Maryland/Washington District of Columbia (MD/DC) area. Finally, flyers were also distributed via study participants to others who might be interested in participating and via social media using an organization (www.trialfacts.com) for online advertising and recruitment through a database of potential participants who are interested in research. When an individual expressed interest in response to direct solicitation or by making telephone contact with the project administrators, the project lead or coordinator conducted a telephone screen using an IRB-approved telephone questionnaire to determine willingness to participate and project eligibility.

Written informed consent for participation was obtained in person on the day of the research education class after the project leaders discussed the details of the project including the goals, benefits, and risks. The major functions of the TBI-PCOR network, participant roles, and duration of engagement in the network were reviewed. A sociodemographic-clinical questionnaire was completed after signing the IRB approved consent form.

Phase 2: direct engagement

Participants were engaged in a daylong series of interactive educational sessions led by a health services expert (QM) with an extensive record of community engagement in mental health research. The sessions included two seminars and two workshops. The first seminar was an introduction to PCOR and covered the following topics: importance and need for patient engagement in care and research; importance of communication and collaboration between clinicians, researchers, patients, and caregivers; roles of patients and clinicians in PCOR research; and values of patient-centered research. The second interactive seminar focused on fundamentals of conducting a research study such as: planning and designing a research project; human subjects research protection, principles of informed consent, and understanding ethical aspects of research; defining outcomes, collecting and interpreting data, and drawing scientific conclusions; defining research strengths and limitations; and effective communication of scientific results to various stakeholder groups using tailored messaging. Each of these seminars was followed by a one-hour workshop focused on interactive learning including reflective discussions, questions, and review and comments,

and suggestions related to the aims and methods of the current proposal.

Five focus groups were conducted at five different times with the project lead and a co-leader moderating the groups. Each group had six participants, except the first, which had five. Each focus group lasted for three hours with breaks of 15 minutes. Prior to the start of each focus group, the moderators provided a brief introduction of the project, overview of the format of the focus group session, defined neuropsychiatric symptoms, and provided examples of such. Neuropsychiatric symptoms were defined as encompassing cognitive problems (e.g. reduced alertness, difficulty concentrating, memory impairments), emotional problems (e.g. sadness, anxiety, irritability), behavioral changes (e.g. anger outbursts, impulsivity, disinhibition), and/or physical symptoms (e.g. sleep disturbances, headache, seizures) that may develop after TBI. The moderators explained that persons with TBI may experience symptoms in one or more of these four neuropsychiatric symptoms categories.

Based upon the informal survey conducted in 2016, a literature review on neuropsychiatric symptoms after TBI, and the input of the project's advisory board members, a semi-structured focus group guide was created which included the following domains of inquiry for each focus group: (a) success and barriers they have experienced in the management of neuropsychiatric symptoms after TBI; (b) strategies to maintain the TBI-PCOR network; (c) research topics on neuropsychiatric symptoms following TBI they would like researchers to address; and (d) health-care policy changes they would like to see implemented in the service of providing more effective treatment to and improving quality of life among people with neuropsychiatric symptoms after TBI. All focus groups were digitally audio-recorded. In addition, co-leaders recorded participant responses in real-time on a flip chart that remained visible to participants during these sessions.

To summarize each focus group, the project leader (VR) also conducted an in-depth interview with a volunteer from the group on the same day the focus group was conducted. This was also audio-recorded. All data collected from these interviews were subsequently de-identified.

Data analysis

The recorded interviews/focus groups were transcribed verbatim. The project leader (VR) and co-leader (LB) summarized and coded the transcripts both manually and using Dedoose qualitative data analysis software. The coding process involved identifying general themes derived from each transcript and recorded data. Codes were then generated based on themes that emerged from the data on the four *a priori* determined domains: 1) success and barriers to psychiatric care; 2) strategies to maintain PCOR network; 3) pertinent TBI mental health research topics; and 4) needed health policy changes aimed at improving quality of life and providing better treatment for people with neuropsychiatric symptoms after TBI.

To establish reliability, transcripts were coded independently by both the project leader (VR) and co-leader (LB). An initial code list was developed to code and sub-code

content by the two independently and later reconciled until coding decisions were at least 90% consistent. Thereafter, each transcript was coded independently by the same two coders. A consensus conference was then held by the four project leaders to discuss the results. Feedback was also solicited from the advisory board and consultants. Questionnaire data was analyzed using Stata version 11.2.

Results

Seventy TBI stakeholders including persons with TBI, caregivers, coordinators/administrators of TBI inpatient/outpatient programs, TBI clinicians, and TBI educators were screened using the criteria mentioned previously (see: Establishment of TBI PCOR Network). Thirty stakeholders met inclusion criteria and were enrolled in the project and 29 participated in the focus groups. Thirteen out of the 30 participants in this project were persons with TBI and caregivers (43%). The two common reasons for exclusion were non-traumatic brain injury and TBI that incurred greater than five years ago. Participants were predominantly women (77%) and Caucasian (77%). African-Americans and Asians represented 17% and 7% of participants, respectively. Table 1 describes the stakeholder types that participated in this project.

Themes were grouped into the four domains identified *a priori* (1): barriers to and facilitators of neuropsychiatric care for persons with TBI (2); strategies to maintain PCOR network (3); pertinent research topics on neuropsychiatric symptoms after TBI; and (4) health policy changes needed to treatment of neuropsychiatric symptoms after TBI and to improve quality of life among persons with such symptoms.

Barriers to and facilitators of neuropsychiatric care for persons with TBI

Participants were asked to name two of the most common barriers and facilitators for successful management of neuropsychiatric symptoms following TBI (Table 2). Stigma of being labeled 'disabled,' 'bad,' or 'crazy' by family and friends as well as inadequate insurance coverage for mental health were identified as major barriers to care of for neuropsychiatric

Table 1. Stakeholders participating in this project.

Stakeholder/Role	N
Persons with TBI	8
Caregivers of persons with TBI	3
Peer caregiver	1
Neurologist	1
Psychiatrist – Military	1
Neuropsychologist – Veteran Affairs	1
Neuropsychologists	2
Clinic coordinators	4
Occupational Therapist	1
Speech Language Pathologist	2
Mental Health Therapist	4
Peer mental health therapist/special needs clinic coordinator	1
Job developer	1

Notes: Peer caregiver refers to an individual with a TBI who concurrently serves as a caregiver to another individual with a TBI.
Peer mental health therapist/special needs clinic coordinator refers to an individual with a TBI who also serves in these roles.

symptoms after TBI. Provision of education on neuropsychiatric symptoms following TBI at the time of discharge from the emergency rooms or acute inpatient rehabilitation facilities as well as having a comprehensive "Do's and Don'ts" caregiver plan were named as facilitators of neuropsychiatric care for persons with TBI.

Participants urged health-care providers who are knowledgeable about TBI and about neuropsychiatric symptoms following TBI to routinely educate family members of persons with TBI about the factors contributing to neuropsychiatric symptoms after TBI as well as the dangers (e.g. isolation, detachment) of using labels such as "crazy" or "impaired" to describe persons with such symptoms. Participants suggested a strategy to overcome the stigma (paraphrased here as): "Find your own people, i.e. people that understand brain injuries and its subtleties; people who really get it; people who are able to talk about it, to come up with cool ideas, and to serve as care champions."

Participants noted that many persons with neuropsychiatric symptoms after TBI do not seek services because they are unable to pay out of pocket for such services. A participant stated, "You shouldn't have to go bankrupt because you have a brain injury or any debilitating disease. We just need better healthcare coverage." Participants recommended the education of insurers on the nature and chronicity of neuropsychiatric symptoms after TBI so that they are able broaden their coverage plans. They also recommended providing incentives such as special reimbursements or loan forgiveness to clinicians involved in the care of persons with such symptoms after TBI so that they are able to offer more services. In addition, they suggested discharge paperwork from emergency rooms and/or acute inpatient rehabilitation facilities to include pamphlets, brochures, or even a flash drive containing information on TBI, common problems after TBI, and locally available resources. Follow-up phone calls by staff after discharge from the emergency room and or acute trauma units, as is often done after-surgery, to check on the patient's progress was another recommendation offered by project participants.

Addressing caregiver burden and the creation of a care plan for the caregiver was identified as an important facilitator of care for persons with neuropsychiatric symptoms after TBI. They opined that caregivers often feel they are left to

their own devices to interpret new symptoms and navigate the healthcare system.

Strategies to maintain PCOR network

Participants recommended four strategies for maintaining a TBI PCOR network (Table 3). These included having a well-defined project, conducting meetings at regular intervals, making participation convenient for participants by combining in-person and virtual meetings at various times, and implementing creative approaches to maintain participant engagement.

With regard to having a well-defined project with a clear mission and member roles established, participants noted that face-to-face meetings are the best approach to discussing project details and progress; at the same time, they also noted that it is not always feasible (due to logistical and administrative issues such as transportation, time commitment, and/or finding a time that is convenient for all participants) to meet in-person. They recommend that alternative methods of PCOR network participant be made available, including webinars or virtual meetings via social media (e.g. Skype, Zoom, GoToMeeting, or a closed Facebook group). Participants also recommended having a project website that can serve as "a central one-stop place" at which all participants can connect and interact. Finally, participants agreed that having a combination of in-person and virtual meetings would be ideal.

They also urged researchers to "think outside the box" and consider other strategies by which to strengthen the interaction between members of the network and to keep the group updated on project progress and/or PCOR network activities.

Pertinent TBI mental health research topics

Participants recommended that TBI researchers be sensitive to patient and family priorities/goals in the development of research projects. Table 4 summarizes the research topics identified by participants and pertinent questions for TBI researchers to address.

The three major research topics included the relationship between TBI and aging, factors influencing positive outcomes after TBI, and substance use disorders before and after TBI. Participants were most interested in having a better

Table 2. Barriers and facilitator to the management of neuropsychiatric symptoms after TBI.

Domains	Themes Identified	Summary of Discussions	Recommendations
Barriers	Perceived stigma	Persons with neuropsychiatric symptoms after TBI are often treated as "crazy/bad/impaired/by family, friends and even clinicians who are not knowledgeable in TBI	Educate family members; Help connect persons with TBI to others who have potential to understand them; Respect individuals with TBI as persons with difficulties versus disabled/impaired
	Poor insurance coverage	Inadequate insurance coverage specifically for neuropsychiatric symptoms after TBI	Education of insurers and incentivize clinicians to provide more services
Facilitators	Management starts in acute trauma period	Education on neuropsychiatric symptoms to be provided in the acute trauma period in emergency rooms and acute care facilities. Acute care facilities to develop long term rehabilitation plans that includes education and management of neuropsychiatric symptoms	Address, educate and guide family members on management of problematic behaviors. Discharge materials from emergency rooms and/or acute inpatient rehabilitation facilities to include literature on TBI and resource guide
	Minimizing caregiver burden	Caregivers are burdened and overwhelmed by neuropsychiatric symptoms that arise following TBI. Addressing this with a comprehensive caregiver plan is beneficial	Create caregiver plan

Table 3. Strategies to maintain PCOR network.

Themes	Recommendations
Define project	a. Project to be defined and agreed upon by all network members. b. Determine project goals, process and outcomes c. Project leaders to be identified and to include a subject matter expert (SME) and a non SME d. Prevent leadership burnout by doing the project in 2 phases and having 2 sets of leaders
Conduct regular meetings	a. conduct lengthy quarterly meetings with shorter bimonthly meetings b. Keep meetings structured with clear start and end time
Make participation convenient	Combine in-person and virtual meetings
Think outside the box	To break monotony and enrich participation and interests a. have guest speakers or subject matter experts for presentations b. conduct workshops or seminars to keep the group educated c. meetings to be occasionally semi-social to help members interact d. consider having meetings in public places such as Church or schools

understanding of cognitive outcomes after TBI, and particularly an improved understanding of the differences between cognitive changes associated with normal aging and those associated with, and are attributable, to TBI (including mild TBI). Participants also identified as high priority research topics: strategies that could be used to improve quality of life after TBI; effective treatment of psychiatric problems such as depression, sleeplessness, and other mood and behavior problems following TBI; childhood psychiatric problems that predispose children to sustain TBI; differences in cultural values (e.g. military versus sports; western versus eastern) that influences treatment; factors associated with reduction of caregiver burden; rates and methods to diagnose TBI in victims of domestic violence; and best apps, herbs/supplements, internet-based therapies, and telemedicine models that can be used to treat neuropsychiatric symptoms following TBI.

Needed TBI mental health policy changes

Participants requested opportunities for health-care professionals to participate in continuing education on TBI and behavioral/mental health. In addition, participants recommended that the public should be educated on TBI via public service announcements and or short documentaries on TBI and neuropsychiatric symptoms following TBI. With regard to documentaries on TBI and its neuropsychiatric sequelae, participants were divided between using a "famous person to beat the stigma versus average Joe on the street" with whom the public could identify. Participants also suggested that the government can incentivize healthcare providers to join the field by expanding existing brain injury training programs and providing other incentives such as loan forgiveness or special loan repayment plans.

Participants acknowledged the importance of peer support programs for persons with TBI and their families, and expressed preference for the term "navigator" over "peer mentor" when describing individuals serving in such programs (i.e. a person with brain injury who has made good improvement since the injury and is willing to help others navigate the recovery path). They recommended local brain injury centers should maintain a list of persons with brain injury who have been educated, trained, and willing to serve as patient navigators; this list can be made available to patients and families. They opined that state and federal government agencies should prioritize funding of low-cost TBI rehabilitation programs to serve the indigent/homeless population as well as 'internet therapies and workable telemental health' models to provide neuropsychiatric care to people living in remote areas and those who are otherwise unable to access neuropsychiatric care (Table 5).

Discussion

This project engaged TBI stakeholders including, persons with TBI, caregivers, physicians, and non-physician clinicians to determine how to make TBI neuropsychiatric care and research more patient-centered. We identified themes and concepts regarding (1): facilitators and barriers to treatment of neuropsychiatric symptoms following TBI (2); strategies to maintain TBI PCOR network (3); TBI neuropsychiatry research topics and (4) policy changes related to neuropsychiatric symptoms following TBI.

Stigma associated with neuropsychiatric symptoms and inadequate insurance coverage for rehabilitation therapies was identified as major barriers to recovery following TBI, consistent with previous reports in both civilian and military populations (6,8). Participants specifically noted a lack of or limited coverage for ongoing mental health care and other rehabilitative therapies such as occupation therapy and or speech-language therapy. Further research will be needed to determine whether the type of insurance (e.g. workman's compensation vs. private commercial insurance) limits accessibility to services such as mental health or rehabilitation services for those with TBI.

In a study on facilitators and barriers to health-care persons with mental illness, Bellamy et al. (9) note that facilitating healthcare requires not only removal of barriers to care but also improving interpersonal aspects of care and providing support systems. Throughout the discussion groups in this project, participants repeatedly emphasized the importance of educating all TBI stakeholders on neuropsychiatric symptoms after TBI. There is a wealth of information on TBI and neuropsychiatric symptoms after TBI on federally supported websites, including those of the Traumatic Brain Injury Model Systems Knowledge Translation Center (TBI MSKTC;10), the US Department of Veteran Affairs (11), the Centers for Disease Control and Prevention (CDC;12), Defense and Veterans Brain Injury Center (DVBIC; 13), Defense Centers for Excellence for Psychological Health and Traumatic Brain Injury (DCoE; 14), and BrainLine.org (15). Videos and written information on TBI and neuropsychiatric/psychological and psychosocial issues are also available on other sites such as Cohen Veterans Network (16), Infinite Hero Foundation (17), the International Brain Injury Association (IBIA, 18), and Ohio Valley Center for Brain Injury Prevention and Rehabilitation (19). Clinicians, as a standard of care, should encourage persons with TBI, their caregivers and family members, and professionals providing healthcare services to these websites and should provide them with the addresses of these websites in written or electronic form.

Table 4. Recommended research topics.

Topics	Pertinent questions
TBI and Aging	a. How does TBI interact or interfere with the typical aging process? b. What are the differences in the neuropsychiatric profile of normal aging versus aging with TBI versus aging observed in patients with dementia? c. Is mild TBI a risk factor for dementia; is there a relationship between severity of TBI and type of dementia; what are the other contributory factors d. Does TBI shorten life span? If so, what are the other contributory factors? How can this be prevented?
Factors that can influence outcomes after TBI	a. Does having a patient navigator or a person who helps guide a person with TBI and the caregiver through the healthcare system effective? b. How do smart app therapies compare to traditional rehabilitation therapies in influencing outcomes? d. What is the effectiveness of alternative interventions, such as yoga, exercise, diet, supplements, neurofeedback, homeopathy, cognitive behavioral therapy, and/or mindfulness training? e. What is the role of insurance in influencing outcomes? f. What is the role of socialization in influencing outcomes? What are the different strategies to improve socialization; what constitutes the best form of socialization – connecting with family/friends vs group therapy.
TBI and addiction	a. Do rates of alcohol and substance use increase or decrease after TBI? b. What are the neurological and clinic-demographic factors associated with decline in substance use after TBI? c. What is the association between location of injury in the brain and substance use patterns post TBI d. What is the relationship between TBI and other types of incident addictions (e.g. Obesity and food addiction; gambling, pornography).
TBI and psychiatric problems	a. What type of childhood psychiatric problems predispose people to sustain TBI? (e.g. ADHD, ODD) b. What tools should be used early on in schools, pediatric office, jail to screen for TBI in persons with ADD/ADHD and how often should it be done? c. Determine effective treatments for depression, sleeplessness and other emotional and behavioral problems after TBI
TBI and culture	a. How do different cultures deal with brain injury? b. How is TBI treated differently in sports culture versus military culture? c. Is TBI treated or assessed differently in different races? (e.g. Caucasians versus African Americans versus Asians)
TBI and sexuality	a. How does TBI affect sexual functioning and sexuality? b. What are the non-harmful and safe methods to express sexuality after TBI?
TBI and the impact on caregivers	a. What kind of support/strategies would help to prevent/minimize caregiver burnout? b. What personality characteristics of caregivers help optimize recovery?
TBI and domestic violence	What are rates and assessment methods to evaluate for TBI in persons with suspected domestic violence given that many do not disclose domestic violence?
TBI and neuroplasticity	a. What are the factors influencing neuroplasticity after TBI? b. Identification of biomarkers to improve effectiveness of medications in treatment of neuropsychiatric problems.
TBI and telemental health	What are the different types and most effective telemental health therapies in managing neuropsychiatric symptoms after TBI?

Table 5. Necessary policy changes.

Policies	Steps to Execute
Implement 360-degree TBI mental and behavioral health education	Training courses, seminars, workshops, documentaries to be made available to patients, caregivers, clinicians, care coordinators, and legislators
Incentives for clinicians involved in care of people with TBI and neuropsychiatric problems	Incentives can be in form of special reimbursements or specific TBI loan replacement programs
Training and compensation for TBI patient navigators	Navigators can guide patients and families navigate the health care system and therefore should be trained and financially compensated
Improve telemental health services	Fund research on TBI telemental health models and adequately reimburse individuals providing TBI telehealth care
Create Government -funded TBI programs	This can be of use to the homeless and the indigent population who are unable to get rehabilitation services they need

It is interesting to note that despite the availability of educational materials on TBI, many participants in this project were not aware of it or wanted more information. Researchers can therefore use this data as a foundation to develop a PCORI grant to evaluate the extant resources on TBI and neuropsychiatric symptoms after TBI and offer recommendations to the field on their improvement and/or further development.

The 360-degree education (i.e. education of patients, caregivers, professionals in TBI neuropsychiatric symptoms) is critical to early diagnosis and alleviation of neuropsychiatric symptoms following TBI. In a study of community mental health centers in Colorado focused on identifying current barriers and facilitators of care of persons with TBI in such settings, Matarazzo et al. (20) note that many mental health providers had limited experience providing services to persons with a history of TBI and co-occurring mental health conditions and required training. This finding is consistent with the perceived need and recommendation for the education of such providers made by the participants in the present project. The participants in the present project also recommended that first-line providers/gatekeepers (e.g. clinicians in emergency rooms, primary care providers, hospitalists, and general psychiatrists) should be educated about the established standards for the diagnosis of TBI and practice guidelines for the management of symptoms following TBI. There are well-accepted national and international standards for TBI diagnosis. They include definitions from the American Congress of Rehabilitation Medicine (ACRM; 21), Veterans Affairs/Department of Defense (VA/DoD; 22), CDC (12), and the Working Group of the International and Interagency Initiative toward Common Data Elements for Research on Traumatic Brain Injury and Psychological Health (23). Similarly, there are established guidelines for the management of symptoms following TBI. They include the National Collegiate Athletic Association (NCAA) Care Consortium (24), the Ontario Neurotrauma Foundation Guidelines for

Concussion/Mild Traumatic Brain Injury & Persistent Symptoms (25), and the VA/DoD Clinical Practice Guideline for The Management of Concussion-Mild Traumatic Brain Injury (22). TBI caregivers should be educated about these resources to both enhance the delivery of treatment and educate persons with TBI and their caregivers about TBI diagnostic criteria and standardized TBI symptom management. Continued collaboration between policymakers and brain injury organizations can help create other dissemination strategies so that these materials are readily available to people who need them – the need for which is demonstrated by the lack of awareness of these materials amongst the participants in our project.

Although some participants suggested that it would be helpful to engage a high-profile person (e.g. a celebrity or other famous person) to serve as a spokesperson for persons with TBI and their families, others preferred that non-celebrities (e.g. everyday people with TBI and/or their family members) serve in this role; with regard to this latter preference, it was noted that some brain injury organizations have successfully had everyday people with TBI and their families serve as their spokespeople, with whom members of the public are more likely to identify than they are with celebrities.

Lack of adequate medical care for persons with TBI, and particularly for those living in rural and frontier areas in the United States and elsewhere is a common problem – and is an especially difficult problem to overcome when specialty-level services are required to effectively treat neuropsychiatric symptoms following TBI. Telemental health and use of smartphones may be one method of addressing this barrier to service provision for this population. Juengst et al. (26) successfully tested a mobile app in a pilot study to assess symptoms of depression and anxiety following TBI. The use of such technologies engenders concerns regarding the protection of patient privacy; but solutions (including robust authentication methods to protect sensitive data) are available and readily deployable (27). Similarly, adherence to published guidelines on the provision of tele-mental health services improves the quality of services delivered and provides solutions to administrative, logistical, safety, and privacy concerns (28).

Project ECHO (Extension for Community Healthcare Outcomes; 29) is another possible method of improving access to specialty-level services for persons with neuropsychiatric symptoms following TBI. This telementoring model connects clinicians with specialists from academic medical centers to provide continuing education and empower community clinicians to treat patients with a variety of illness through regular sharing of knowledge and skills via weekly videoconferences.

Many participants in the present project expressed dissatisfaction with discharge planning from emergency rooms and acute inpatient rehabilitation facilities and suggested having a peer mentor navigator guide them during the first year following TBI would be very helpful. Peer mentoring has been found to be successful in the management of geriatric depression (30), geriatric diabetes (31), and in weight loss in persons with chronic mental illness (32), and this approach was regarded by project participants to be well-suited to improving outcomes among persons with neuropsychiatric symptoms following TBI.

Several strategies were suggested by participants to maintain PCOR network. Their recommendations are consistent with the six PCORI engagement principles: reciprocal relationships, co-learning, partnerships, transparency, trust, and honesty (33).

Participants expressed interest in and commitment to TBI neuropsychiatry research, and they identified a broad range of potential research topics in this area, ranging from pediatric TBI and childhood illness such as ADHD to aging and TBI. Some of the research questions raised by participants in this project have been explored. To name a few, they include: TBI and aging (34), TBI and dementia (35–37), TBI changes in cognition and social functioning in the chronic TBI period (38), associations between TBI and alcohol consumption (39), patterns of alcohol use after TBI (40), behavioral and mental health outcomes after TBI (41–43). A project for future consideration therefore is one that evaluates the effectiveness of current methods of disseminating TBI research findings. Findings from such research would not only inform future dissemination but also provide stakeholder feedback on TBI research priorities, healthcare policies, and funding decisions.

The present project was limited by the relatively small number of participants and its geographic restriction to the mid-Atlantic region of the United States. While the use of a stakeholder group representing persons with all severities of TBI, a variety of caregiver types, and a diverse group of professionals is a strength with respect to the range of inputs provided, it also limited the specificity of the input provided to relevant subgroups of persons with TBI (e.g. children and adolescents, adults, or older adults; persons with concussion or mild TBI, moderate TBI, or severe TBI; persons early in their recovery and those with chronic neuropsychiatric sequelae; etc.). Nevertheless, the major strength of this project is its focus on the neuropsychiatric sequelae of TBI, the breadth, and depth of the feedback from participants on the care of persons with such symptoms, the research agenda in this area, and healthcare policy changes needed to enhance recovery/rehabilitation and improve quality of life among persons with neuropsychiatric symptoms following TBI.

Conclusion

In summary, the goal of this project was to create a network of stakeholders interested in participating in patient-centered outcomes research focused on neuropsychiatric symptoms following TBI. In addition, the project has served as a platform to engage participants in discussions on a variety of topics on TBI neuropsychiatric topics with the ultimate goal to highlight the importance of patient-centeredness in clinical care and research.

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